

Types of tinnitus enquiries received by Deafness Research UK

1) What treatments/support available- Questions about CBT, TRT, hearing aids.

“Do you have any information on treatment/support I am entitled to on NHS, as my local Tinnitus unit has been extremely unsupportive and they didn't offer me a follow up appointment for over 18 months and now I've had to be re-referred by my GP. When I did see a consultant, the treatment I was offered wasn't helpful either (rehabilitation) and my consultant was very 'medical model' and he dismissed the recent research on Tinnitus I'd printed off from the web on causes/treatments saying that his newly qualified colleague would be interested in “that kind of thing”.

“My 74 year old mother has been profoundly deaf for approximately 13 years... During this time she has suffered from tinnitus...It seems to be getting worse and is causing her lost sleep...All the advice I have been able to find from her GP or online etc is for people with some hearing - white noise, avoiding silence, hypnotherapy etc, which are no good to her with her almost non existent hearing. Are there any self-help relaxation techniques you can recommend?”

“Would you please send me a copy of the Managing Tinnitus leaflet. I have had Tinnitus for a number of years but quite recently the noise level has increased significantly and would be grateful for any advice.”

Also questions about complementary therapies such as hypnotherapy, auriculotherapy, reflexology, acupuncture.

2) Potential treatments found on the Internet- supplements and products such as:

Tinnitus Care, Tinnitool, Tinni-fix, <http://tinnitus-cures.info/> DHA supplement, ginkgo biloba, Lipoflavonoid

“I was recently contacted by someone who had found out about a laser therapy for pain and he was wondering if it might help tinnitus...I must admit I can't see how it might help tinnitus, but I thought I would write to you to see if you had any comments.”

“I am a tinnitus sufferer; I found this link while looking around the net. <http://tinnitus-cures.info/> I am pretty sceptical about these 'cures' as I know that people with tinnitus are quite vulnerable and easy prey. Has your organisation heard of this and could you comment on whether it would be worth me purchasing it?”

3) Developments in tinnitus research-and taking part in research

rTMS, hyperbaric oxygen therapy, stem cell research, acamprostate

“I have suffered with chronic tinnitus for over ten years, it's unbearable and driving me insane. Like most sufferers I've had no real treatment and just have to try and live with it. Has there been any progress in the research, if so we would love to hear about it.”

“Do you have any information on intratympanic drug injections for tinnitus sufferers?”

“I'm a 36 year old healthy male, and like many I'm unfortunately suffering from Tinnitus and would like to know how I can become involved in the research of this. I wish to volunteer for any experimental treatments that may be available in the U.K (or abroad if expenses are covered). I currently live in the Lancashire area, however, I have my own transport and can travel”

4) Help with finding a specialist

"I know of a sufferer who really needs help and has not had much support from their GP... they are based in the Cheshire area and it would be useful to know what centres they could go to be assessed and receive the best treatment they can. They are happy to travel if they have to. In addition to this can any treatment that they are assessed as requiring be funded by the NHS."

5) Searching for a cause/ identifying things that may aggravate tinnitus such as:

Medications, ear syringing, medical conditions such as diabetes, thyroid problems etc. Also associations between tinnitus and landline telephones, electro-magnetic activity in the atmosphere.

"I was wondering if you could give me some advice on my husband's tinnitus. He has had this condition for about 12 years which has gradually got worse. Every time we go to the doctors they say there is nothing they can do. The other thing is that my husband has been taking Wafarin for the last 14 years for multiple emboli (blood clots on the lungs) would this have any thing to do with this."

"Is there any evidence to show that being dehydrated and lying horizontally in bed can cause a morning roar? My tinnitus is usually a hissing sound, which I can use a masker for, but this morning this is almost obliterated by a sound like the Underground in my head"

"I am deaf in both ears, but the right ear (where I have Tinnitus) is worse than the left. For years, people kept giving me aids to wear, but because I have straight ear canals and little purchase they kept falling out so were abandoned till about 3 years ago when I got a set of in-the-ear with an adaption piece made specifically for me to 'lock' them in place, so I started to wear them every day, and my Tinnitus got worse, now its really loud. Have the aids in increasing the sounds I hear each day (work as a design CAD engineer so at a computer all day) made or contributed to the increase in Tinnitus in 'learning' my brain with normal sounds are now there all the time and therefore become Tinnitus?"

6) Children with tinnitus (questions not as common)

"The ENT consultant suggested finding online information in order to help my 9 year old cope with tinnitus. He has no hearing problems but did have some fluid behind the ear drum last year which now has resolved. The tinnitus is in one ear and he describes it as sounding like a bee buzzing in his ear. His behaviour and concentration are a cause for concern at the moment and I am trying to give him as much help to cope with the irritation of the tinnitus as I can. I would appreciate any assistance you can give me please."

7) Also questions about pulsatile tinnitus, being able to alter tinnitus.

Hyperacusis enquiries

1) Enquiries relating to children

"I have a four year old son who seems to be developing normally. He was recently diagnosed with seizures but has since been on medication to control them. Over the last month or so he has progressively become more sensitive to loud sound. Examples would be when I call him or his siblings from another room, opening the bag inside a cereal box, shaking of a toy such as a maraca. He has always been afraid of extremely loud noises such as fireworks and canons, which would be expected. I do not know if I am over reacting but I am concerned. Do you think I should contact an ENT or give it some more time. I am aware that you cannot give me a diagnosis but just an opinion would be helpful"

"Our 5 year old boy may have sound sensitivity. He cannot concentrate in groups, and doesn't like class room or playground noise. We have seen a centre in London which offers

assessment at £350, and the treatment (of cost unknown) is 10 days, which is almost impossible for us to undertake and afford. Are you able to tell us of anything that we might do at home to help him?"

"I have a son who is 8 months old. I have found that my son gets very distressed and unhappy when he is with other babies when they make noise. My health visitor has suggested that he may have hyperacusis/hyperacusis. I'd like to know more about it and some help with working out whether he does have this or not. Is it something that is treatable? I am becoming increasingly concerned as I have to return to work in a few months and poor little guy will have to go to nursery. An environment where he is very unhappy. Is there a way to rule in/out if he has this condition at all?"

Question Information Officer has put to Deafness Research UK advisor

"We have received an enquiry regarding a 3 and a half year old boy who gets distressed at playgroup when the room becomes too noisy and often puts his hands over his ears when he hears hand dryers, drills etc. Although he has been seen by ENT they say he is too young for them to do anything and that he might grow out of it. The enquirer's friend however, who is an audiologist has mentioned hyperacusis to her and as such she has contacted us for advice."

2) Looking for a specialist

Examples of enquiries to Deafness Research UK sent to advisors (Dr Marriage)

Children

"An enquirer would like to have his son tested for hyperacusis and is looking for a specialist who would be able to help. The boy is currently undergoing tests for autism and the father says that because of this it is difficult to get the hyperacusis recognised. They have been to see their GP but he hasn't referred them to anyone. The father says he has been aware of his son's distress at certain sounds since he was a few months old but has only recently heard about hyperacusis."

"This is an enquiry regarding a nine year old boy. His has good hearing but the audiologist mentioned he might have hyperacusis. When his hearing was tested a second time the same conclusion was reached but nothing else was said about it. The boy has been tested for dyslexia and the results were inconclusive. His schoolwork is being affected and the mother is very keen for him to be tested. She says they live in Banbury and would be happy to go to any hospital in a 30 mile radius; she would also consider going privately."

"A GP has suggested that a child with learning difficulties may have hyperacusis but hasn't made a referral. The family live in Tower Hamlets and their local hospitals are Royal London and Mile End. Do you know anyone to which she could be referred please."

Adults

"I have an enquirer with hyperacusis who was sent by his GP to a specialist who hadn't heard of it. I suggested he went back to his GP to ask for another referral but he wasn't very keen to do this so I said I would see if I could find out anything for him. He would like suggestions as to who he could be referred to his local hospitals are Bournemouth and Poole."

"A lady has started to avoid situations because of certain noises (she says she had to leave the room at work because someone was coughing). She has been to the doctors about it but says they have put it down to depression and focused on that. I understand there is a link between depression and hyperacusis, but do you think it would help her to see a specialist about hyperacusis and should she go back to her GP to try and get a referral?"

"I have just read about noise generators and wondered how I would be tested for one and how much they cost. I was diagnosed as having early onset lewy body dementia and have noticed that, noise sometimes can cause a lot of distress. I did not have this until around 2003 when I was given this diagnosis, but sometimes the sound of a bag of crisps being opened, is like living through an enormous hangover. I have spoken to my GP about this, but he did not seem to be very interested."